



Keeping the Beat

Fall 2019

Offering information, resources and emotional support to families dealing with congenital heart disease.

In this Issue

The 10th Annual Heart Beats Family Fun Run



The 10th Annual Heart Beats Family Fun Run took place on Sunday, October 20th. Over 500 people participated in the 10 km run, 5 km run/walk, and 1 km Marvel-themed kids' race. It was a beautiful, brisk Fall morning, but participants kept warm with their jaunty Heart Beats toques, hand warmers, and the pancake breakfast put on and donated by the Lions Club of Calgary.

The top race finishers were:

- 10 KM, FEMALE | Alice Goudie
- 10 KM MALE | Tyler Perry
- 5 KM, FEMALE | Jackie Onyszko
- 5 KM, MALE | Simon Ong



Race results can be found at www.startlinetiming.com/en/races/2019/heartbeat

The annual Heart Beats Run brings together CHD families, friends and supporters and this year was no exception. For a second year in a row, the three largest teams were Team Kevin with 40 members, and Lauren's Angels and Team Alysha which each had over 60 members.

The Run is Heart Beats' largest fundraiser and we are very pleased to report that \$40,000 was raised this year. These funds will be used to continue to assist and support children with Congenital Heart Defects and their families. We are so grateful to all who fund raised and made donations.

The top fundraisers were:

- Lil'H, Team Adam, and Wilson Glowach who each raised over \$2,500
- Stella Koslowski of Hope Holly Lincoln who raised over \$3,000
- Lauren's Angels who raised over \$5,000.

For more on the run, turn to page 6



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What's been happening in the world of **HEART BEATS**

Heart Beats Family Camp



The Heart Beats Family Camp was held on September 6 – 8, 2019 at Camp Evergreen in Sundre, Alberta. As usual Camp Evergreen provided the families activities to enjoy, such as Wilson ball, ropes course, zip lining, wagon rides, horseback riding, bracelet making, archery and so many more including their new 'flying squirrel' activity. The glow-in-the-dark Pac-Man adventure was put on by some of the heart dads with help from some of the older children. It was highly anticipated and once again was a hit with all ages! The accommodations and meals were incredible as were the staff, animals and land. There were 22 families in attendance this year, including some that this was their first year coming to camp. Some parents expressed what this weekend meant to them and their children; we at Heart Beats share the same sentiment. Thank you for coming to support, lean on, laugh with and watch how incredible we are as a 'family'. Heart Beats extends a big thank you to the Calgary Children's Foundation and to CP for their much appreciated support of our Family Camp.



What's been happening in the world of **HEART BEATS**

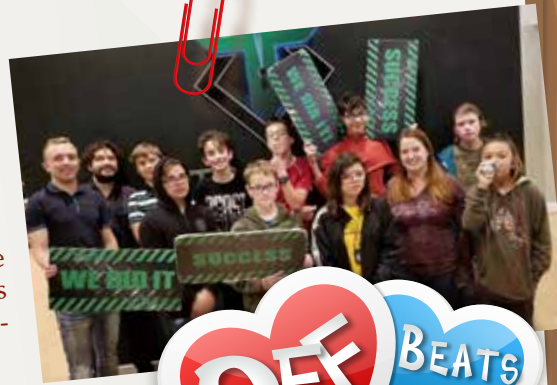
Dad's Night Out



On October 28th, local Heart Dads and their kids had an opportunity to attend a Calgary Hitmen hockey game in style. CP donated their box at the Saddledome to the group who enjoyed deluxe seating and a delicious dinner buffet. The event was capped off by a visit from Farley the Fox who delighted the children in attendance. Thank you to CP has Heart for your generosity



On October 19th the Offbeats group had a very fun evening which began with burgers and milkshakes at Peter's Drive In, then on to Trapped where they challenged their problem-solving skills in the escape rooms. They welcomed new members and always welcome more. Offbeats is for CHD youth in grades 7 to 12 and is led by Offbeats "alumni" Vittorio, Sam, Meggie & Jesse. For more information about upcoming events, email offbeats@heartbeats.ca.



Heart Beats

Heart Beats is a purely volunteer-run organization by parents whose own children have congenital heart defects, and we are always looking for other people to join us in giving back to this community we have all been personally touched by. We meet four times a year as a board but also have one-off opportunities for you to volunteer as well, whether it be hosting a mom or dad's night or a parent & tot playdate. We invite you to reach out us by emailing us at info@heartbeats.ca. We also welcome ideas for future events or initiatives.



Moms' Night Out & Dads' Night Out

Moms' & Dads' Night Out meet several times throughout the year. Whether your heart child is an infant, teen or adult, we welcome you to visit and chat with other moms and dads about parenting kids with CHD or just to take a break with people that understand. Grandparents are welcome too! An appetizer or dessert and a non-alcoholic beverage is covered by Heart Beats. The group will meet on various dates and locations around Calgary, so please check your monthly email for upcoming events.

Your Support in Action

Donations made to Heart Beats Children's Society of Calgary are used to provide information, resources and support to families living with congenital heart defects in Southern Alberta. The following is just a few ways your donations have helped:

- Financial assistance to families traveling to Edmonton for their child's heart surgery through our "Helping Hand Fund";
- Supplemental equipment for the Alberta Children's Hospital Cardiology Clinic;
- Items of encouragement for children undergoing extended hospitalization;
- Camp Scholarships for children with congenital heart disease.



Donating to Heart Beats

If you wish to contribute to the support of families of children with congenital heart defects, you may do so in the following ways:

Mail

Heart Beats Children's Society of Calgary
Box 30233, Chinook Postal Outlet
Calgary, AB T2H 2V9

E-transfer

to our Heart Beats Treasurer at
treasurer@heartbeats.ca (remember to include your mailing address to receive the receipt).

Credit Card

through CanadaHelps.org (a link can be found on our website at www.heartbeats.ca)

Donations received from June ~ October 2019

Thank You

Kathryn Schneider Akomeah

Tom Becker

Cathy Howarth

Kate Price

In Honour Of The Badrudin Family

Heidi Smethurst

Rebecca Kylo

In Honour Of Deacon Rhynold

Kathy Winstanley

Calgary Children's Foundation

Generocksity

Ladies Auxiliary Fraternal Order Of Eagles

Newell 4-H Agricultural Committee

Thomas Mccarthy

Through United Way Of Greater Toronto

Uli Ng

Through United Way Of Calgary

Greg Plante

Through United Way Of Alberta Capital Region

Anonymous

Through Benevity

Anonymous

Through Canadahelps.org

Anonymous

Through Paypal Giving Fund

Anonymous

Through United Way Of Calgary

Anonymous

Through United Way Of Greater Moncton

& Se Nb Region

Spotlight on Donation: Generocksity - Box to The Beat

In February 2019, the Generocksity Calgary team took on an opportunity to get involved with Heart Beats and raise funds through a vibrant and unique event called "Box to the Beat." Generocksity is student-run and a nationally recognized not-for-profit with various chapters in North America that all aim to change the way young people give to local charities. By collaborating with Rumble Boxing and TrueBuch Kombucha, the team was able to raise over \$400! Kiersay, a seasoned boxing instructor and a member of the Generocksity team, hosted not one but two boxing classes where all proceeds were donated. Participants also got a free glass of Kombucha to drink after class! Peers were able to sweat it out for Heart Beats while having a good time in Rumble's top-of-the-line studio. Whether participants were avid Heart Beat donors, or simply just there to work out for a good cause, Generocksity successfully hosted the first Box to the Beat event and was happy to donate all proceeds to Heart Beats Calgary.



HEART BEATS TEAM RUN HIGHLIGHTS



This year we entered our first ever Heart Beats run in honour of our little guy Thomas. It has been a big year for our family - in February we learned that our fourth child would be born with Tetralogy of Fallot, in June our baby boy Thomas was born, and in September he underwent his first open heart surgery up in Edmonton.

The past year has certainly felt like we've been on a rollercoaster ride, but we are truly fortunate for all the blessings and support received along the way. It's been extremely comforting to know that we have an exceptional support network here in Calgary, which of course includes our cardiologist, the nurses and entire cardiology team at the ACH...as well as support received from the Heart Beats Society.

Feeling as though we'd overcome a mountain of challenges, the timing couldn't have been better for us to pay some of it back by participating in our first Heart Beats run. Thomas' team included his brothers and sister, cousins, aunt/uncle, and friends. The kids especially had a blast (I think ours were the last to leave the event) and they are already talking about fundraising and training for next year's run!

-Nadia Monaghan



Thank you to all our volunteers without whom we could not carry out the event. Thank you also to the following individuals and businesses who donated items and services for the raffle, silent auction and run:

- Golden Bhatia
- Rebecca Chamberlain
- Derek Davidson
- Lauren Klukas – Fitless Flavor
- Tony Nicastro
- Alpine Helicopters Inc.
- Columbia 1938 & Todd Jensen
- Country Lane Farms
- Fairmont Banff Springs
- Fire Exit Theatre – Val Lieske
- FlyerShop
- Good Life Fitness – Calgary Deerfoot City
- Hairloom 85
- Hot Yoga on 17th
- Hot Yoga on Crowfoot
- Jackie O Monat Independent Market Partner
- Lions Club of Calgary
- Luc's European Meats – Sonia Alle
- Mark Anthony Wines
- Pursuit
- Superstore – Deerfoot Meadows
- Superstore - Seton
- Shoplift
- Westin Downtown Calgary



SUBSCRIBE TO "KEEPING THE BEAT"

If you would like to receive Keeping the Beat directly to your inbox, please email us at info@heartbeats.ca. Alternatively, you may pick up a printed edition at the Cardiology Clinic or download a copy from our website at www.Heartbeats.ca. Note: E-mail addresses will be used only to distribute Keeping the Beat newsletter and notices of Heart Beats events; e-mail addresses will not be given to any third party.





Family Fun Run

Donations from the 2019 Run

Paul Aris
Evan Birch
Claudette Chisholm
Melissa Eastcott
Heather Elliott
Eryn Forsyth
Jen Gardiner
Negar Golbar
Derek Goudie
Angela Jesse
Burce & Isabelle Kleiber
Kamila Krol-DeProphetis
Clara Langen
Mary Langen
Wes Llewelyn-Williams
Gail MacKean
Kendra Mainprize
James McLean
Mary Catherine Murray
Brad Niznik
Bruce Niznik
Kristen Niznik
David Patton
Grayson Perry
Tom & Nadine Potts
John Quinn
Sophia Scondrianis
Andy Sifer
Kristin Slute
George Templeton
Kim Tran
Kim Twohig
Shauna Twohig
Rachel Varghese
Erika Vorhies
Katie Wakaruk
Lindsay Wilson

Megan Andrews

Nancy Anderson
Cheryl Andrews
Holly Congram
Kari Holder
Julie Jenkins

Teena Ketchmark
Vi & Dale Olsen

Alex Bennett - Run for Remi

Julie Fearey
Karen Fredrickson

Anastasia Burgess

Linda Aubin
Sterling Anderson
Paul Andrew
Chad Burgess
Brandie Chan

Mark Foster

Mathieu Bourgeois
Candice Cantave
Chris Dyck
Shinell Foster
Oaitse Hellard
Luke Juneau
Allana Lau
Dion Mahadeo
Kyle Mahadeo
Adam Maucieri
Rebecca Miller
David Roberts
Cory Sabean
Elliott Sarbah
Melissa Sarbah
Janine Varuna
William Young

Wilson Glowach-Super G

Beverly Brailsford
Leslie Coe
Jodie Crawford
Steve Cszasz
Donna Ferguson
Alexander Glowach
Larry Glowach
Angela Glowasky
Brad Kingsmith
Elaine MacDonald
Bev McKee
Susan Raven
Patrick Roelofsen

Corrine Stillings
Jeff Stillings
Roland Stillings
Shirley Sommer
Victoria Tims
Gale Tunnicliffe
James Wagner
Cynthia Wright
Shawna Wright

Magnum McDowell

Elisha Beckie
Annette Christensen
Sandra Christensen
Michelle Cody
Migizi Fleury
Lenore McDowell
Shantelle Malley
Andrea Stevens

Mathias Pollard

Lori Sunde-Cooper
anonymous

Jamie Rozema-Stinson

Marisa Galitz
Nicole McDougall

Justina Sherstabetoff

Misti Christensen
Lindsay King
Pamela Matlock
Chelsey McDermot-Fouts
Cindy Middleton
Tracy Munro
Reufudina Mustedanagic
Toni Pasolli
Arlue Rickard
Blair Sanderson
Tara Sansome
Myrtle Saunderson
Jen Sherstabetoff
Justina Sherstabetoff
Ruth Sherstabetoff
Nancy Strath
Leslie Warren
Travis Warren
Michael Williams
Randal Williams

Ryan Williams

Rachel Varghese

Brandi Dyck
Donna Jakowec
Maureen Kehler
Ruth Morris

Morgan Wyntjes

Megan Bambrough
Oran & Garry Bambrough

A+

Susan Harbidge
Amelia Torgerson

Aliyah's Amigos

Lenore Brown
Mark D'Costa
Michael Dekker
Allison Duffett
Douglas Erickson
Kyle Groves
Cori Haines
Derrick Hanna
Steve Hazlehurst
Jennifer-Anne Jamieson
Chris Kaiser
Kristin Kells
Judy Lester
Daphne Newell
Trevor Ollen
Jacy Rapke
Preston Scholz
Sanjit Singh
Jeff Sklar
Heather Suttie
Mark Thibeault
Amanda Trottier
Jennifer Wood
ATB Financial

#DontNeed2

Supporting Baby Warren

Brittaney Nason
Maddie Warren
Erin Wilkins

Hope, Holly, Lincoln

David Abday
Leah Abday



Mike Abday
Angela Aube
Garth Ayres
Andrew Bell
Fabrizio Chiacchia
Mandee Davidson
Brody Elliott
Ron Franklin
Kristyn Frederick
Shelby Hamilton
Dennis Kerber
Sylvia Kerber
Ian & Charlotte Kirk
Charles Klettke
Amy Koslowski
Anita Koslowski
Jamie Kotlewski
Derek Murphy
Angela Ottenhof
Angela Patterson
Jeremy Pono
Manuel Rieder
Marko Tse
Neil Vorel
Tim Walterhouse
Lindsay Wilson

Lauren's Angels

Warren Armstrong
Stuart Bartwicki
Clint Brennan
Kirsten Exall
Rainer Exall
Karen Fozard
Shannon Hughes
Trent & Fiona Hunter
David Kipp
Agnieszka Kustra-Rau
Colleen Lewis
Jani Long
Karen Marshall
Dennis Rattray
Dave Rossiter
Paul Rossiter
Stephen Scott
Brett Stevenson
Richard Stevenson
Kathy Tough
Stacey Wee

Lil' H

Hannah Black-Wallis
Kathy Bruce
Matt D'Amour
Brynn Dockerty
Brooke Hewson
Kelly Hewson
Kyke Hewson
Sandra Hewson
Tracy Knourek

Bryce Lastiwka
Jacklynn Mannen
Max Rosanova
Drewe Salahor
Kris Schaffer
Daren Sharpe
Krysta Wageman
Tamara Wetzstein
Elbow River Marketing Ltd.

Sebastian's Team

Daniel Burnell
Shantel Burnell-Lyttle
Leslie Decarie
Corey Lyttle
Rhys Lyttle
Victoria Lyttle

Team Adam

Mike Bond
Peter Blanchard
Cameron Foss
Sarah Geddes
John Gulak
Keith Hemke
Sarah Hemke
Donna Holstine Vander Valk

Candace Kalyn
Jamie Kanashiro
Kelly Kanashiro
Jenn Martin
David Richardson
Stacie Sceviour
Kaitlin Sharpe
Tyler Stuart
Casey Vandenboer
Kylie Warne
Russell Wilson
W. Brett Wilson
Paul Wright
Craig Yeliga
Stacie Zbrodoff

Team Alysha

Sarah Beattie
Jody Bencharski

Sarah Carter
April Cooney
Dale Cooney
Ron Elson
Shauna Harrison
Natalie McDougall
Jeannine Oliphant
Jamie Pedersen
Tracy Pedersen
Chris Peters
Peter Smythe
Shandel Thomson
Curran Wearmouth
Greg Wearmouth
TC Energy Corporation

Team Kevin

Blair Arneson
Megan Arneson
Carol Goodwin
Gail Hart
Brenda Hemsing
Beverly Lutz
Donald Rutherford
Douglas Rutherford
Jackie Saby
Jon Saby
Sherry Waddle
Jocelyn Wilson
Thomas Wilson

Team Marie

Laurent Foulonneau
Boris Kuhn
Amanda Morelli
Ed Moroz

Team Michelle

Keith Kotelko
Orest Kotelko
Patty Kotelko

The Sweetest Hearts

Anita Dodd
Allison Foreman
Cassandra Godkin
Tiffanie Harrington
Janie & Henry Hollman
Real & Diane Mangonon
Drew McGuire
Kate McGuire
Kristina McGuire
Samuel McGuire

Thomas' Ticker Team

Leah Aldous
Brigitte Bedard
Jennifer Blaney
Debra Cadrain
Jill Carlsen
Natalie Carson

Lyse Ann Clark
John Devine
Erin Ellard
Jennifer Ezekiel
Candace Gates
Wendy Gill
Lindsay Grosser
Genevieve Leblond
Gerald Luciuk
Lesia Luciuk
Darcy Macleod
Nadia Monaghan
Vincent Ostryzniuk
Flavie Pritchard
Maxime Pritchard
Christie Teterenko
Erin Ward
Venesa Wheatley

Tiny's Heart

Jerry Tiessen

We Have Heart

Kelly Collen
Karnell Goebel
Jan Isenor
Rebecca Kylo
Joelle McKenzie
Contender Holdings Ltd.

Xander and Friends

Carleen Beynon
Derek Enns
Mary Murray
Heather Rombough

Thank You

CAMP DEL CORAZON



Camp del Corazon is an organization that provides a medically supervised, residential summer camp for children ages 7-17 who are living with heart disease. Located on Catalina Island, 22 miles off the California coastline, the camp has served approximately 300 children each year since 1995. The camp offers an opportunity for heart kids to be 'normal', to forget their ailments, and to connect with others who have had similar experiences and scars. Camp del Corazon offers the camp free of charge; the only cost for campers is transportation to and from the camp.

Campers from Calgary have been attending Camp del Corazon for the past five years. This past August, three young people from our Heart Beats community, ranging in age from 9 to 15, attended. First time camper, Anna says:

This summer I was lucky enough to attend Camp del Corazon. It's a Heart camp off the coast of California. We stayed in little cabins on the beach, and filled our days with activities like snorkeling, kayaking, archery, bingo, and crafting. I made many new heart friends. It was an amazing experience, and I'm so thankful I was able to participate.



Registration for the 2020 Camp Sessions will begin in January 2020. For information on how to apply for camp, visit www.camp-delcorazon.org.

Heart Beats has a scholarship fund that will cover the plane fare for first-time campers and provide subsidies for repeat campers. For more information, contact treasurer@heartbeats.ca.

CANADIAN BLOOD SERVICES

Every minute of every day, a patient in Canada needs blood. Some of these patients are children with CHD undergoing heart surgery. You never know when you or someone you care about may need blood. Canadian Blood Services is always looking for more donors.



1 in 2 Canadians will either need blood or know someone who will at some point.

More regular donors are needed to maintain a strong national inventory of blood & blood products to meet patient needs.

Over 100,000 new blood donors are needed in Canada this year to keep up with demand.

Giving blood is one of the most direct ways you can help someone.

Encourage your family and friends to donate.

Making an appointment to donate has never been easier.

Download the Give Blood app, call 1 888 2 DONATE (1 888 236-6283) or book an appointment at blood.ca.

Walk-in appointments are also available at all locations.



One little ticket, one big lift.

Kids Up Front

Kids Up Front aims to put deserving kids and their families in seats that would otherwise go empty at events. If you hear of an event that your child would enjoy attending they will take requests! If you wish to be put on a list for "anything Ballet" for example, that is acceptable. In exchange all you have to do is mail out a hand made thank you card to Kids Up Front.

To be included on the Kids Up Front opportunity mail out, message kuf@heartbeats.ca.



REFLECTIONS OF A HEART CHILD SIBLING

by Janelle Wiebe

My name is Janelle Wiebe and I am Isabelle Wiebe's older sister. Isabelle was born with hypoplastic left heart syndrome and has had four open heart surgeries.

I was less than two years old when Isabelle was born, so my first memories of Isabelle being in the hospital were during her third surgery, when I was five years old. During this surgery, my parents and I stayed at my grandparents' home in Spruce Grove. I remember one day asking my Grandma how long we were staying there, and her responding that she didn't know. I remember being very confused by this, and also wondering why one of my parents were always gone.

I am now twenty years old, and Isabelle is eighteen. As I've been reflecting on my experience of being the older sibling of a heart child, I've had four main things come to mind that I'd like to share with parents of heart children.

The first is that Isabelle is my hero. I've watched her go through four open heart surgeries (two that I can remember) and countless other medical procedures with so much bravery. Even though she is my younger sister, I look up to her and try to emulate the courageous and easy-going nature she has displayed through everything she's had to go through.



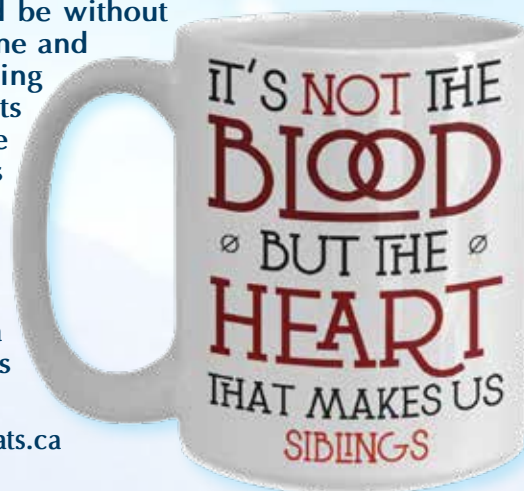
That being said, the second experience I've had is always wishing there is a way that I could go through some of the medical procedures or take on some of the concerns for Isabelle. I often feel bad that I'm the child who has had it much easier in our family. I must make it clear that absolutely no one in my family or community has ever done or said anything to make me feel this way, but this is something I've put on myself.

Thirdly, as the sibling of a heart child, I've at times felt that I am "out of the loop" when it came to Isabelle's condition. My parents were given all the information from doctors so they could make informed decisions for her health, and Isabelle has always been given age-appropriate explanations of her condition. However, I have found I've often had to ask for details regarding her condition and have found out about new concerns and treatment plans later than everyone else in the family. Finding time to give age-appropriate explanations and updates to the siblings really helps us out a lot. When I was thirteen, Isabelle suddenly got critically ill and had to be airlifted to Edmonton. I didn't know what was going on at first and was extremely worried and scared. However, when my mom explained to me what the doctors found and how they were going to treat it, this calmed me down a lot and allowed me then to just let my parents focus on Isabelle.

Lastly, I have no idea where I would be without the community that has surrounded me and my family during these times. During

Isabelle's surgeries, I was very lucky to get to stay with my grandparents and be surrounded by relatives while Isabelle and my parents were at the hospital. When Isabelle got very sick when I was thirteen, literally hundreds of people came together around me and my family and took care of and supported me during this time. It is so important for siblings of heart children to have a strong support network especially while their sibling is in the hospital and parents are gone frequently. Heart Beats is an incredible foundation to support families of heart children, and because of my experiences I believe a sibling's support group would be an extremely beneficial resource for siblings of heart children to build up that support network.

If you are interested in the new Heart Beats Sibling group, email info@heartbeats.ca for more information.



THE FORCE is with this young transplant patient.

Mason Thomas was six when he received a new heart at the Stollery Children's Hospital in Edmonton. He asked to see his damaged one but it was discarded after the surgery. To help the now eight-year-old understand why he needed a new ticker, experts printed two 3D models of the organ from his CT scans.

One model of the red muscle and its pumps was put inside a tiny TIE Fighter for the young Star Wars fan. The fictional space-flying vehicle is used by the Galactic Empire to fight the rebel force in the popular movie franchise.

"It's amazing," Mason said when he was given the models Wednesday.

"They show why my old heart couldn't work and why I needed a new one."

Mason was born with hypoplastic left-heart syndrome, a rare congenital defect. His heart failed after a second surgery and he was on a transplant wait list for more than three years. Dr. Charles Larson with the hospital's pediatric cardiac intensive care unit came up with the idea for the 3D models.

"This is an anatomically accurate representation of Mason's heart, with colours to help him understand how the blood and oxygen were flowing, and which parts of his heart were too small and failing," he said in a statement.

Larson worked with industrial design students through the Faculty of Medicine and Dentistry. Staff and students at an engineering faculty workshop then did the 3D printing.

The team has made 10 heart models so far and plans to make 10 more to be shared with other patients and families as well as with medical students, Larson said. Mason's mother, Brandie Thomas, said he is a logical kid who likes to know how things work.

"The question of why this happened to him bugs him the most, and seeing the heart helps give him some of the answers of what was wrong with him and why he was so sick."



Heart Beats and Social Media

Find us on Facebook... and Twitter...and Instagram



Staying in touch with other heart families and joining in fascinating conversations has never been easier! Our Facebook group is always growing, so stay in the loop by searching Heart Beats from your Facebook page or click on the link at our website to become a part of this expanding group.



Heart Beats is on Twitter! Staying on top of community news and upcoming events has never been easier. Simply follow our tweets at: twitter.com/HeartBeatsChild.



MEDICAL BINDER APP

In 2017, the 22q Foundation Australia & NZ began development of a 22q patient coordination web portal and App. The App allows families and patients with 22q to co-ordinate and have access to their our own records, reports and care via an online digital portal.

Did you know this App can also be utilized for all types of Medical children including Heart Kids?

The App will allow families and patients to have all their records, appointments, treatments centres, physicians or therapists list, medication list and assessment reminders with them wherever they are without carrying large binders.

The App allows the user to :

Set up a personal profile for yourself and your loved ones

Tick off the assessment checklist and receive annual reminders for the recommended assessments due each year (The Assessment Checklist was formulated and published in the Practical Guidelines for Managing Patients with 22q11.2 Deletion Syndrome.) This is not mandatory if not required

Create a list of emergency contacts

Create a list of medications with dosage and reminder (it also allows you to keep a history of your medications)

Set up a list of care, medical and treatment centres including physicians , therapists or anyone who works with you or your 22q person and includes Google Maps

Store a list of your immunization records

Create a list of appointments, meetings, events etc... and be reminded via notifications

Create a list of symptoms and allergies including treatment, severity and the ability to upload photos, reports and files

Create a list of surgeries, treatments and helpful information

Send the personal medical profile including reports or files directly from the portal and App to any person via email

Join the 22q community directory and connect with people near you (optional)

Join the 22q Registry and be a part of research (optional)
(Privacy Policy Applies)



This is an example of the medical report that can be emailed to yourself or anyone you wish to send it to....



Medical profile for Charlotte KAMPER generated on 08/18/2018 12:32 AM

Name: Charlotte KAMPER
Age: 19
DOB: 01/09/1999
Gender: Female

Address: 2567 Lagoon Road
Phone: 494502563
Email: nmkamp@westnet.com.au
Key Information: CNI: 2209452047 IFR: 389431042 Diagnosed with 22q11.2 Deletion Syndrome 12th May 2004 - Dr Patricia Wright Documents attached

Name	Phone	Email	Relationship
Megan Prokes	0218452940	mprokes@liberty.com.au	Mum
Maria Kamper	0438261104	mariakamp@westnet.com.au	Sister
Maria Kamper	0404592543	mariakamp@westnet.com.au	Sister

Name	Dosage	Frequency	Reason
Paracetamol	1	Daily	Anxiety & OCD
Zoflora	20	Daily	Thyroid

Medication Notes: Followup 15-16/10 Tuesday and Thursday

Physician	Contact Number	Specialities	Location
Stacey Callen	02 6330 0988	Disability Employment	George Street Medical Centre
Dr Rozhan Aamer	031270755	OT	Westmead Childrens Hospital
David Fitzsimons	029893000	Speech Language Pathologist	The Find Lab
Dr Linda Campbell	0422877064	Clinical Psychologist	George Street Medical Centre
Dr Michale	03125255	Australian Hearing	Australian Hearing
Jessica Kennedy	02 6381 0503	Hearing	Australian Hearing

Physician Notes: Stacey Callen - Carer

Jessica Kennedy: assisted devices connect to tv , to computer, phone , camps for hearing equipment.

Description	Date
A combined injection for diphtheria, tetanus, whooping cough (pertussis)	03/06/2018
HPV (Human papillomavirus) (2 doses)	01/06/2018
Pneumococcal	01/06/2018
Diphtheria, tetanus, whooping cough (pertussis), gale	09/01/2004
Diphtheria, tetanus, whooping cough (pertussis)	02/26/2007
Measles, mumps, rubella, chickenpox (varicella)	01/01/2001
Haemophilus influenzae type b (Hib)	01/01/2001
Measles, mumps, rubella	09/01/2003
Oral drops for otitis	09/01/2003
Pneumococcal	11/03/1999
A combined injection for diphtheria, tetanus, whooping cough (pertussis), hepatitis B, pertis, Hib (Haemophilus influenzae type b)	11/03/1999
An injection for Pertussis B	09/01/1999

Immunisation Record Notes

Symptom or Allergen	Reaction	Severity
Small Left Superior Vane Carin Draining into Coronyr Sinus		Mild
Hypercholesterolaemia		Mild
Laryngeal web (anterior)	If this separation does not occur and a web of tissue is left across the laryngeal inlet it is called a laryngeal web or glottic web	Moderate
Learning disabilities (math calcuag, reading comprehension)		Moderate
Obsessive compulsive disorder		Moderate
Social immaturity		Moderate
Hypothyroidism	Too little thyroid hormone. Symptoms include weight gain, constipation, dry skin, and sensitivity to the cold. Also called underactive thyroid.	Moderate
Narrow external ear canals	In most cases, blockage of the ear canal with wax is a harmless event.	Moderate
Protrusion		Moderate

Created on 08/18/2018 12:32 AM by 22Q Team

Medical profile for Charlotte KAMPER generated on 08/18/2018 12:32 AM

Symptom or Allergen	Reaction	Severity
Impulsiveness		Moderate
Mild conductive hearing loss	Conductive hearing loss usually involves a reduction in sound level, or the ability to hear faint sounds.	Moderate
Narrow external ear canals	In most cases, blockage of the ear canal with wax is a harmless event.	Moderate
Frequent otitis media	Otitis media is an infection or inflammation of the middle ear.	Moderate
Overfolded helix	The helix is the curled ridge made of cartilage on the outer edge of the ear.	Moderate
Overt, submucous or occult submucous cleft palate	The condition described as submucous cleft palate is when the palate appears to be structurally intact, but there are clefts and/or muscular abnormalities underlying the skin's surface.	Mild

Allergy Notes
Hypercholesterolaemia: Diagnosed May 2004

Name	Address	Contact Number
Verto	227 Honeick St, Bathurst NSW, Australia	02 6330 0988
Ochre Medical Centre	1470 Panorama Avenue, Bathurst, NSW, 2795, Australia	029 6331 9444
Marjorie Park Medical Centre	2 Technology Place, Marjorie Park, New South Wales, 2139, Australia	029 9812 3966
Australian Hearing	122 Kite St, Orange, NSW, 2800, Australia	029 6793 0300
The Find Lab	The Boulevard, Dumblah, New South Wales, Australia	0423977064
Westmead Childrens Hospital	179 Hume Highway Road, Westmead, New South Wales, Australia	0298450300
Bathurst Base Hospital	345 Honeick Street, Bathurst, New South Wales, Australia	0263303311
George Street Medical Centre	115 George Street, Bathurst, New South Wales, Australia	63125355

Preferred Care Centre Notes
Ochre Medical Centre: Dr Ross Wilson



Children's Wish Foundation and Make-A-Wish® Canada Announce Merger to Grant More Wishes to Children Across Canada

United organization will have the ability to grant 25 per cent more wishes each year

TORONTO, October 2, 2019 – Today, Children's Wish Foundation of Canada and Make-A-Wish Foundation® of Canada announced that the two charities are merging with the goal of granting the wish of every eligible child across the country. United as Make-A-Wish® Canada, the organization will have the ability to make a greater difference in the communities it supports, increasing its ability to grant wishes for children with life-threatening illnesses by 25 per cent more each year.

"This is a significant and exciting time as our two organizations join forces on a quest to bring every eligible child's wish to life," said Michele Augert, Chair of the Inaugural Board of the united organization. "We applaud the vision and leadership of both legacy organizations for taking such extraordinary steps to make us one united and strong team ready to revolutionize and grow wish granting in this country."

Both organizations have long operated independently with similar guiding missions, visions and values; and every year have provided hundreds of children with life-threatening illnesses the opportunity to realize their most heartfelt wish, giving them the strength to endure their treatments and build resilience. The union is the result of extensive, collaborative and thoughtful planning involving expert advisors and leadership from both organizations. The integration will take place in a phased approach over the next 12 to 24 months.

Together, the organizations aim to grant approximately 2,600 wishes in 2022, which is approximately 1,000 more wishes than granted independently in 2018.

"We are bringing together our collective best practices, relationships and strengths, making us stronger than ever and able to serve even more children and their families," said Chris Kotsopoulos, Co-CEO of the new combined organization. "With up to 6,000 children in Canada facing a critical illness and complex medical needs each year, this is an important step toward our goal of ensuring every eligible child's life-changing wish is granted." states Jennifer Klotz-Ritter, also Co-CEO of the united organization.

A wish is an integral part of a child's treatment journey and research shows a wish can give kids the strength to fight against, and even overcome a critical illness. Results from a Wish Impact Study that surveyed parents, health professionals, and volunteers, show that a wish-come-true empowers children to fight harder against their critical illnesses. 71 per cent of adult former wish kids believe the wish experience contributed to saving their lives.

"In Canada's crowded charitable sector, it's great to see two organizations with similar missions come together to have an even greater impact on our communities." said Bruce MacDonald, President & CEO, Imagine Canada, a national organization that strengthens and supports Canadian charities and not-for-profits. "This is a great example of how charities can take a creative approach to putting recipients first to make a real long-term difference."

Visit thepowerofonewish.ca for more information.

Share the Power of a Wish®

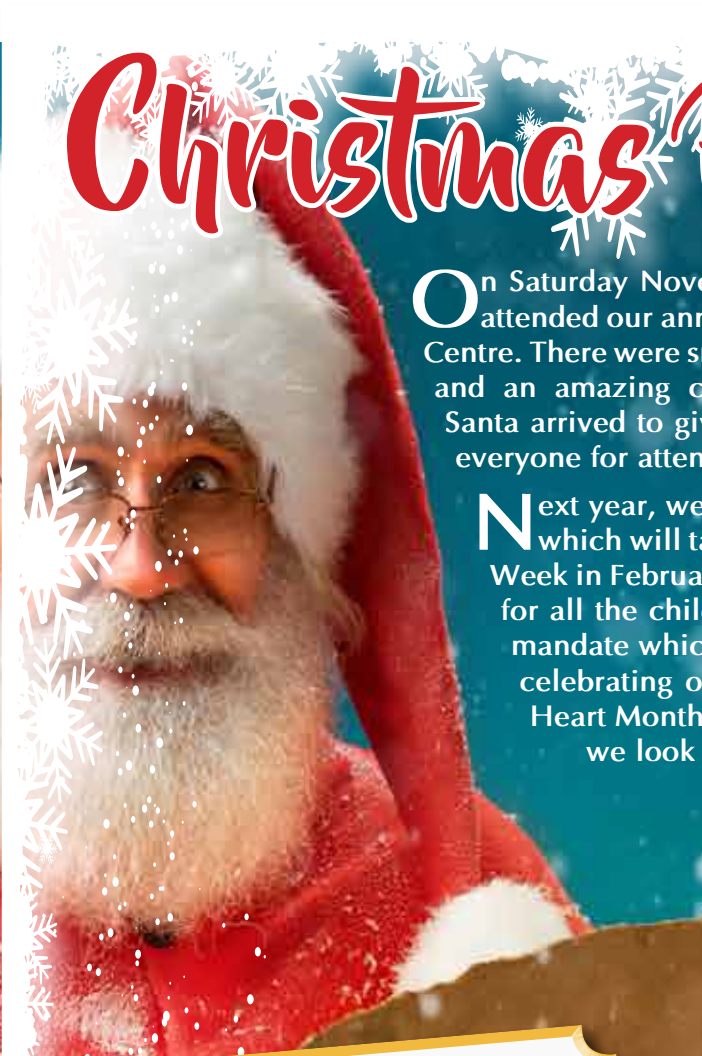


Christmas Party

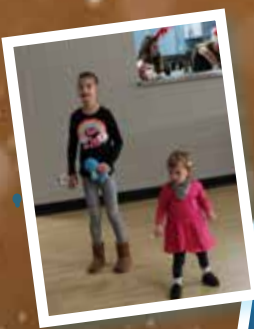


On Saturday November 30th 2019, 134 Heart Beats family members attended our annual Christmas Party at the Silver Springs Community Centre. There were snacks, door prizes, a 50/50 draw, great conversations and an amazing crafts station that kept everyone entertained until Santa arrived to give gifts to all 68 children in attendance. Thank you everyone for attending.

Next year, we will be moving the party to a Celebration of Hearts which will take place during Congenital Heart Defect Awareness Week in February. We will have a similar format, including presents for all the children in attendance, but we will be focusing on our mandate which is to raise awareness of CHD. What better way of celebrating our Heart Families than to throw a big party during Heart Month. We hope that you will all embrace the change and we look forward to celebrating with you in February 2021.



This Christmas season Heart Beats also provided 9 hampers to families in need to help the with this upcoming festive season.



A hand is shown placing wooden blocks to spell out '2020 REVIEW'. The top row consists of four blocks with the numbers '1', '9', '2', and '0'. The bottom row consists of six blocks with the letters 'R', 'E', 'V', 'I', 'E', and 'W'. The background is a soft-focus image of a hand holding a block.

Hear Beats had another successful year in supporting children with congenital heart defects and their families. We hosted a variety of events, including a skating party in February, a Beach Day in July, the Family Camp in September, the Annual Family Fun Run in October and the Christmas party in November. In addition, we held three Moms & Dads Nights out, several Offbeats events, and we sponsored three kids to attend Camp del Corazon in California.

Because we keep our administrative costs to a minimum, we are able to allocate the vast majority of our funds to directly supporting heart families. This year that included over \$40,000 in gift cards distributed to our heart families traveling to the Stollery in Edmonton for surgeries and other procedures, hotel vouchers, iPads for the ACH Cardiology Clinic to entertain the young patients during appointments and procedures, and Christmas hampers to nine heart families going through particularly challenging times.

These events and supports are only possible because of the donations received throughout the year from private and corporate donors.

Our biggest fundraiser of the year continues to be our Family Fun Run in October. This year we celebrated our 10th Annual Run and together we were able to raise \$40,000 ! We encourage all of you to register for next year's run and to spread the word to your friends, family and colleagues. Registration details will be published in our next newsletter.

This year, we became a participating charity with Shaw Birdies for Kids presented by AltaLink which matched donations made to Heart Beats through them from February to September by up to 50% which resulted in an extra \$10,000 for Heart Beats! The Watson Family Foundaton has supported Heart Beats for a number of years. The Calgary Children's Foundation again supported our Family Camp by donating \$5,000. There were also a number of other initiatives both from industry and the general community with funds raised by Animus Capital Partners, ATB Financial and The Order of Fraternal Eagles, to name a few. The South Slope 4H Club in Brooks raised a steer and donated the proceeds to Heart Beats. 4 year-old Asher set up a lemonade stand in order to raise money for our community and Magnus raised money for Heart Beats at his birthday party. We are always amazed at the creative ways our community supports one another.

As you know, Heart Beats is run entirely by volunteers. We meet several times per year in each other's homes. We are always looking for fresh ideas, so if you are able to help out, please drop us a line at info@heartbeats.ca.

Thank you all for your support and commitment to this community. We wish all of you a very Merry Christmas and we look forward to another great year ahead.



BIRTHDAYS

Happy birthday to Roman who turned 12 on October 9th. He started junior high this fall and is looking forward to meeting other youth at Offbeats events



Wilson Glowach, born with TGA and VSD, celebrated his 5th birthday November 6, 2019 and his 5 year heart-anniversary on November 17, 2019. He was just recently cleared for another year by cardiology and is doing amazing!



Jacob Randall celebrated his 10th birthday on October 18. He is an amazing big brother, funny and adventurous.



Eysen turned 5 on October 4, 2019. This year has been such a big year for him. Eysen welcomed his baby brother with so much love and has proved to be a wonderful big brother. He also faced his fear of water as he completed his swimming lessons and is moving on to preschool.



Hunter turned 6 on November 14, 2019. Happy Birthday!



Heart Beats

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Vice-Chairperson Tara Exall

Treasurer Patty Wiebe
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Disclaimer: Any personal opinions/ comments expressed in this newsletter are not necessarily those of the Heart Beats Board of Directors. All submissions for the newsletter will be accepted; however, we reserve the right to publish in whole, in part or not at all. Remember, your best source of medical information is always your physician.



Design & Production:
Paul Warren, Immersion deSign Inc.
Dad of a Heart Child
www.immersiondesign.ca

More Pictures with Santa....



Happy Holidays to
you and yours....

